

***DELIVERING END-OF-LIFE CARE TO
INDIVIDUALS WITH HIV/AIDS:
A NATIONAL APPROACH***

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(SPNS) Program, HIV/AIDS Bureau, Human Resources
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HIV/AIDS AND PALLIATIVE CARE

- *HIV/AIDS remains a fatal disease*
- *Medically underserved and hard to reach populations increasingly affected by HIV/AIDS*
- *Treatment advances have slowed disease progression and permit medical management*
- *Delivery of palliative care presents unique challenges*

CHALLENGES IN DELIVERY OF HIV/AIDS PALLIATIVE CARE

Disease-specific:

Stigma of disease

Fear of contagion

Erratic, episodic disease

Multiple medical problems

CHALLENGES IN DELIVERY OF HIV/AIDS PALLIATIVE CARE (Continued)

Population-specific:

Stigmatized lifestyles

Lifestyle-related treatment issues

Non-medical needs related to life circumstances

Access to medical services

Maintaining continuity of care

CHALLENGES IN DELIVERY OF HIV/AIDS PALLIATIVE CARE (Continued)

Community-specific:

Impoverished communities

Limitations in resources

Limitations in agency linkages

OVERVIEW OF PALLIATIVE CARE INITIATIVE

- *Special Programs of National Significance (SPNS) supports innovative service delivery models in palliative care*
- *Palliative care projects target medically underserved and hard-to-reach populations with HIV/AIDS*
- *Demonstration projects testing different models of palliative care delivery and service*
- *Evaluation and Support Center established at Columbia University to foster evaluation and replication of demonstration projects*

HIV/AIDS PALLIATIVE CARE PROGRAM ELEMENTS

Populations targeted:

Homeless

Substance Abusers

Incarcerated

Multiple-diagnosed mentally-ill

Uninsured

Medically underserved

HIV/AIDS PALLIATIVE CARE PROGRAM ELEMENTS (Continued)

Services provided:

Palliative care

Links to hospice care

Case management

Social services

Family psychosocial support

Spiritual support

Community-based housing

Personal care services

HIV/AIDS PALLIATIVE CARE PROGRAM ELEMENTS (continued)

Site of service delivery:

Client's home

Community hospice residence

Community clinic

Hospital outpatient clinic

Hospital inpatient unit

Long-term care facility

Jails

HIV/AIDS PALLIATIVE CARE PROGRAM ELEMENTS (continued)

Composition of care team:

- Physicians*
- Nurses*
- Social workers*
- Clergy*
- Health aides*
- Psychologists*
- Addiction workers*
- Outreach workers*

PALLIATIVE CARE PROJECT: VOLUNTEERS OF AMERICA

<i>Geographic locale:</i>	<i>Urban (New Orleans, Louisiana & Los Angeles, California)</i>
<i>Care team:</i>	<i>Nurse, Social Worker</i>
<i>Population served:</i>	<i>Seriously-ill jail inmates</i>
<i>Services provided:</i>	<i>Case management, linkages to hospice programs, linkages to social services</i>
<i>Service model:</i>	<i>Transitional case management</i>
<i>Project summary:</i>	<i>Provides transitional case management to seriously-ill inmates to assure ongoing delivery of palliative care services regardless of ultimate placement</i>

PALLIATIVE CARE PROJECT: CATHOLIC COMMUNITY SERVICES

<i>Geographic locale:</i>	<i>Urban (Jersey City, New Jersey)</i>
<i>Population served:</i>	<i>Homeless multiply-diagnosed</i>
<i>Care team:</i>	<i>Multidisciplinary (Social worker, Nurse, Health aide)</i>
<i>Services provided:</i>	<i>Case management, home care, social services, family counseling/support, links to hospice agency</i>
<i>Service model:</i>	<i>Community residential housing</i>
<i>Project summary:</i>	<i>Establishes a community residence to provide terminally-ill homeless with the housing and personal care workers required to access hospice care from private agencies</i>

PALLIATIVE CARE PROJECT: AIDS SERVICES CENTER, INC.

<i>Geographic locale:</i>	<i>Rural (Northeastern Alabama)</i>
<i>Population served:</i>	<i>Poor, uninsured, homeless</i>
<i>Care team:</i>	<i>Multidisciplinary (Physician, Nurse, Social Worker)</i>
<i>Services provided:</i>	<i>Medical, case management, social services, counseling, housing</i>
<i>Service model:</i>	<i>Hospice care</i>
<i>Project summary:</i>	<i>Delivery of home and clinic- based hospice care by an HIV community clinic-based hospice team, also established a community residence for terminally-ill homeless clients</i>

PALLIATIVE CARE PROJECT: UNIVERSITY OF MARYLAND, BALTIMORE

<i>Geographic locale:</i>	<i>Urban (Baltimore, Maryland)</i>
<i>Population served:</i>	<i>Substance abusers, homeless, multiply-diagnosed, uninsured</i>
<i>Services provided:</i>	<i>Palliative and hospice care</i>
<i>Care team:</i>	<i>Multidisciplinary (physician, nurse, social worker, chaplain, addictions specialist)</i>
<i>Service model:</i>	<i>Augmented hospice model</i>
<i>Project summary:</i>	<i>Provides palliative and hospice services to terminally-ill patients at community clinics, hospital HIV unit and long-term care facility</i>

PALLIATIVE CARE PROJECT: MONTEFIORE MEDICAL CENTER

<i>Geographic locale:</i>	<i>Urban (Bronx, New York)</i>
<i>Population served:</i>	<i>Substance abusers, homeless, poor</i>
<i>Care team:</i>	<i>Multidisciplinary (physician, psychologist, nurse, social worker, addictions specialist, chaplain, outreach worker)</i>
<i>Services provided:</i>	<i>Medical, case management, counseling, spiritual</i>
<i>Service model:</i>	<i>Augmented palliative care model</i>
<i>Project summary:</i>	<i>Hospital-based palliative care team delivers care to seriously-ill patients in ambulatory care network, AIDS center, nursing and substance abuse facilities</i>

MULTI-SITE DOMAINS OF DATA ELEMENTS

Client Demographics

Client Medical Status

Client Medical Treatment History

Client Service Utilization

MULTI-SITE DOMAINS OF DATA ELEMENTS

(continued)

Quality of Care: Palliative Care Outcomes Scale (POS) [Higginson]

Quality of Life: Missoula-Vitas Quality of Life Index [Byock]

Psychological Functioning: Mental Health Inventory (MHI-5) [Berwick, et. al]

Physical Functioning: Rapid Disability Rating Scale (RDRS-2) [Linn]

Symptoms: Memorial Symptom Assessment Scale [Portnoy]

CASE STUDY ELEMENTS

Description of key program elements:

Target population - eligible/served

Services provided

Service objectives/client outcomes

Staff/units providing services

Staff/agency coordination of services

Chronology of key implementation events:

Challenges faced

Barriers encountered

Strategies utilized

Successes achieved

Failures experienced

ILLUSTRATIVE EVALUATION QUESTIONS

How effective is the program in providing appropriate care?

*Sufficient symptom management, appropriate quality of care,
appropriate quality of life*

How efficient is the program in maintaining continuity of care?

*Fewer emergency room visits, shortened length of “active treatment”
hospital stays, fewer diagnostic tests*

What is needed to facilitate program replicability?

*Staffing requirements, change in referral systems, integration of
services, inter/intra-organizational linkages*

SUMMARY

- *Provision of appropriate care and services to individuals dying from HIV/AIDS is an emerging challenge*
- *Palliative care program initiatives are intended to stimulate adoption of improved forms of service delivery to medically under-served and hard-to-reach populations*
- *Information garnered from these demonstration projects will aid providers and policy makers in program implementation in other settings*